



DBS Tips for Prospective Patients & Family Members

By Susan Heath, RN, MS

Email: susan.heath@va.gov

Tel: 415.221.4810 x 2505

“What will DBS help me with?”

DBS usually WILL improve...

- Motor function
- Tremor
- Rigidity
- Limb dystonia
- Daytime sleepiness
- Sleep patterns
- Postural instability & freezing gait (if previously helped by dopaminergic meds)
- Medication wearing-off effects (smooths fluctuations)

DBS usually will NOT improve...

- Freezing gait during “on” period
- Postural instability during “on” period
- Issues with handwriting
- Speech and swallowing problems are generally not improved, but they sometimes get better for a short period of time.
- Functions lost over 4 years ago will not reappear with DBS.
- Symptoms that are not improved with current medication “on” state will not improve with DBS.

Commitment and patience

Deep brain implants take time and effort to work correctly. They require commitment and patience on the part of the patient and a dedicated family member to embrace the use of this mildly complicated implantable system. The patient and family member will learn to use a handheld device to adjust the power or settings in order to help control some motor symptoms of Parkinson’s disease.

Assistance with medications

In the first month or so after this procedure, senior patients often need increased assistance with their usual medication dosing. ***A significant caregiver/spouse/family member must be available to help.*** It can be surprising when a post-implanted person is not as independent right after the surgery as they were before; this is a *transient* condition, but common for patients in their 60s or 70s. A designated family member or friend ***must step in*** and become actively involved in the medication dosing and assessment of Parkinson’s symptoms in the post-operative period for about one month. With a little teaching and willingness to take charge, the patient can usually resume their usual independence.

Learn to describe common motor symptoms after surgery

Parkinson's and other movement disorder symptoms change after surgery and it is important to learn how to describe common problematic symptoms. This requires learning the vocabulary terms to communicate a problem to the clinician:

<i>Term</i>	<i>Description</i>
Tremor	Involuntary shaking, typically of the arm or leg, often at rest. Hand tremor may manifest as the classic "pill-rolling" movement.
Dyskinesia	Sudden, unintended muscle movements such as an arm lifting on its own or swaying of the body trunk.
Stiffness or rigidity	Inability of the muscles to completely relax.
Dystonia	Prolonged muscle contractions that lead to unusual posturing or repetitive movements. May be painful.
Freezing	A sensation of being uncontrollably stuck in place when trying to walk.
Festinating gait	Stooped, forward-leaning gait characterized by short, shuffling steps.

Usually a patient has one or two of these problems, if only occasionally, and the symptoms must be identified in order to help titrate the device and medications for better comfort and control.

Timing of the symptoms

It is also important to assess *when* during the day the symptoms tend to occur. Things to think about before you call for help with a specific issue:

- *Does the problem occur when you wake up in the morning?*
- *Does it occur at night? Are symptoms present all day long?*
- *Does the problem occur continuously or intermittently?*
- *Does it happen before or after you take your medications?*

If a symptom lasts all day long, it may be a result of the stimulation. Sometimes decreasing the stimulation using the handheld device may help. If the symptom is intermittent, it is more likely related to the dosage and timing of medications.

Troubleshooting motor symptoms

<i>Symptom</i>	<i>What to try</i>
Tightness or bothersome dyskinesia	Try reducing the voltage on the device.
Symptom is intermittent	Most likely related to the dosage and timing of Parkinson's medications, not the stimulation.
Usual Parkinson's state or under-medicated state	Try increasing the stimulation using the "up" arrows.
If increasing the stimulation is not an option	Consult the clinician about increasing the Parkinson's medication (such as Sinemet 25/100) to improve symptoms. The increased dose may be needed until a repeat appointment is scheduled to reprogram the device.
Persistent new "soreness" in a limb OR changes in speech	This may be a side effect of the device. Temporarily turn off the device to see if the problem fades; if the symptom is a side effect of the implant, the settings can be adjusted at the next programming appointment.

Sources:

Giladi, N. (2002). *Parkinson's disease: diagnosis and clinical management*. New York: Demos Medical Publishing. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK27448/>

Michael J. Fox Foundation. (2014). *Living with Parkinson's: dyskinesia and dystonia*. Retrieved from <http://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?dyskinesia>

National Institute of Neurological Disorders and Stroke. (2014). *NINDS deep brain stimulation for Parkinson's disease information page*. National Institutes of Health. Retrieved from http://www.ninds.nih.gov/disorders/deep_brain_stimulation/deep_brain_stimulation.htm

National Parkinson Foundation. (2014). *What are the symptoms of Parkinson's disease?* Retrieved from <http://www.parkinson.org/Parkinson-s-Disease/PD-101/How-do-you-know-if-you-have-PD->

Revised April 2014 by Lauren Stroshane, SFSU Graduate Nursing Student